Special Addition

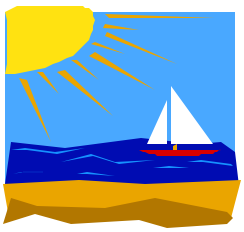
children with special health care needs spring/summer 2004

A NEWSLETTER FOR MISSOURI FAMILIES

A publication of the Missouri Department of Health and Senior Services, Special Health Care Needs

In this Issue

Federal Viewpoint



Family participation and satisfaction: DELIVERING ON THE PROMISE

by Diana Denboba, Public Health Analyst, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration

Families of children and youth with special health care needs. Youth with special needs. Communities. Partnering organizations, like the American Academy of Pediatrics, Family Voices, and March of Dimes. State Children with Special Health Care Needs (CSHCN) programs. All have been working with the national Division of Services for Children with Special Health Needs (DSCSHN) to create and implement a new model for serving children with special health care needs. The model is community-based, family-centered, and culturally competent. It is coordinated care, delivered within comprehensive and integrated systems of services. To be successful, this model must include the following core outcomes:

- family participation and satisfaction,
- access to a medical home,
- access to affordable insurance,
- early and continuous screening,
- easy-to-access, community-based service systems,
- services necessary to make the

please see page 2

Local Viewpoint

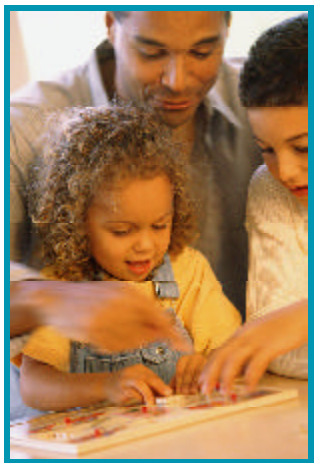
Special Health Care Needs success stories

Missouri Department of Health and Senior Services, Special Health Care Needs (SHCN) provides services daily for numerous individuals with special needs. These are just a few of the success stories that this assistance has generated:

√ SHCN provides service coordination for a young man living with his parents who both work outside the home. This young man has a medical condition that required a tracheotomy several years ago. Until recently, he had been able to provide self-care. As his medical condition deteriorated, he

please see page 3

DELIVERING ON THE PROMISE



continued from page 1

transition to adulthood.

This new model of care serves as a way to achieve the *Healthy People 2010* (*HP 2010*) objective of increasing the proportion of states and territories that have service systems for children with special health care needs. *HP 2010* provides an opportunity to move forward on full implementation of systems for children with special health care needs and to have a 10-year focus on achieving and measuring success for all children with special health care needs.

Delivering on the Promise, the Health and Human Services self-evaluation to promote community living for people with disabilities, was developed in response to the President's New Freedom Initiative, which reduces barriers to community services and independent living. It charges the Maternal and Child Health Bureau (MCHB) with taking the lead to develop and implement a plan to achieve appropriate community-based service systems for children and youth with special health care needs and their families.

The model (including the above core outcomes) developed by DSCSHN and partners serves as the basis for this New Freedom Initiative plan. The implementation activities for the core outcome, family participation and satisfaction, address the following goal: to recognize that families are the ultimate decision-makers for their children and to encourage them to participate in making informed decisions. This goal is also part of a national effort to have this new model of a service system in communities by 2010.

Family-centered care

The DSCSHN and our partners know that families have been struggling for many years to find services for their children with special health care needs. Their expertise is often overlooked or ignored. Moreover, families often require additional family support and information on community services, such as transportation, respite care, care coordination, translation and interpretation services, and financial support for services. But, such information has often been hard to obtain, hindering families' ability to make informed decisions with providers about the health and related needs of their children.

For years, DSCSHN has promoted family-centered care and family-professional partnerships. Family-centered care is based on the recognition that most children, including children with special health care needs, live within the context of families, which may include biological, foster, and adoptive parents, grandparents, other family caregivers, and siblings. Family-centered care ensures that (1) the organization and delivery of health care and support services meet the emotional, social, and developmental needs of children; and (2) the

please see page 7

A medical home is an approach to providing access to quality health care services in a cost-effective manner in a primary health care setting. Families and providers act as partners to identify and access all the medical and nonmedical services needed to help children and their families achieve their maximum potential.

Special Addition is a free newsletter published twice a year for families of children with special health care needs. MedWrite News, Inc., Cincinnati, Ohio (513-791-8582), provided the newsletter design and layout of the national news.

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HRSA
Health Resources and Services Administration
Maternal and Child Health Bureau

continued from page 1

could no longer provide self-tracheostomy care as well as other activities of daily living.

Through Medicaid's HCY Program, Private Duty Nursing (PDN) services were provided while his parents were at work. He has since graduated to the Physical Disabilities Waiver (PDW) when he turned 21; the PDN services were continued. Eventually he had surgery, which alleviated his self-care problems, and he is now capable of providing his own care. The PDN services were discontinued, and he remains at home by himself, and provides his own care.

√ Special Health Care Needs received a hospital referral on a newborn with skeletal and cardiovascular abnormalities. The infant was hospitalized and placed in several foster homes until he was transferred at 13 months to a foster home in the service coordinator's area. He was enrolled in the Healthy Children and Youth (HCY) and the First Steps (FS) programs, which have provided many services, including Service Coordination.

This baby boy was a medically fragile infant, and his initial prognosis was not good. The provision of skilled nursing visits through the HCY program, and occupational, physical, and speech therapies, as well as special instruction through the FS program, allowed him to thrive and to develop way beyond the initial expectations of everyone who was initially involved with him.

These early medical and developmental interventions were the first steps in his transition to a more healthy and successful life. He has transitioned from the FS program to the school district in a regular Early Childhood Special Education (ECSE) classroom and has been adopted by a new family. He has begun to say a few words and was walking and playing with his peers at the time of his transition.

SHCN staff are dedicated to assisting persons with disabilities. Please call 1-800-451-0669 if you need assistance. SHCN staff will help to determine if your child may qualify for enrollment in one of our services.

Paper trails & letter writing

from Wright'slaw

You can use letters to build relationships, identify and solve problems, clarify decisions that were made and not made, and motivate people to take action.

Train yourself to write things down, this will help you protect your child's interests. If you have a dispute with the school, your letters are independent evidence that support your memory. Documents that support your position will help you resolve disputes early.

When you write a letter, think about what you want your letter to accomplish. Edit letters, they make a good impression. When you write a letter, think about the powerful decision-making Stranger who can make things right.

These articles will help you write effective letters:

* The Art of Writing Letters *

In this article you learn to use tactics and strategies when you write letters to the school. You learn about the Blame Approach and the Story-Telling Approach; the sympathy factor; first impressions; pitfalls; and the powerful decision-making Stranger.
http://www.wrightslaw.com/advoc/articles/DRAFT_Letters.html

* Using Story-Telling to Persuade *

See how one father used the story-telling approach of letter writing when he asked the school district to help his son. Do you see Joe through his father's eyes? Do you understand why the parents removed Joe from the public school program? What should be done to help Joe?
http://www.wrightslaw.com/info/ltrs.persuade.james.htm

* 12 Rules for Writing Great Letters *

If you have a problem with the school or concerns about your child's program, you must document your concerns in writing. This article includes 12 Rules for Writing Letters, and editing tips.
http://www.wrightslaw.com/advoc/articles/12rules_letters.htm

SAMPLE LETTERS TO THE SCHOOL

For more information about letter writing, please go to:
http://www.wrightslaw.com/info/ltrs.index.htm

If you have a copy of Wrightslaw: From Emotions to Advocacy, turn to page 331. You will find more than a dozen letters that you can tailor to your circumstances:

*Request your child's file
*Request a meeting with the school team
*Document a discipline problem
*Express appreciation
*Document an IEP problem
*Decline a request / reschedule a meeting
*Request a meeting with a teacher
*Request a review of your child's educational records
*Request an evaluation for special education services
*Request test scores as standard

please see page 4

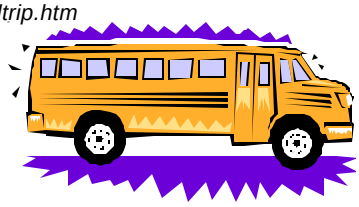
continued from page 3

scores and percentile ranks
*Follow-up letter after IEP meeting to document unresolved issues / requests
*Ten-day letter to withdraw child from public school

Learn more about Wrightslaw: From Emotions to Advocacy: http://www.wrightslaw.com/bks/feta/feta.htm

Summer safety - field trips

from www.metrokc.gov/health/childcare/fieldtrip.htm



Children, staff, everyone likes the excitement and the adventure of a field trip especially when the weather turns warm. A little advanced planning can help make your trip a successful occasion that the children will remember with pleasure. Here are some suggestions for developing your safety plan:

FIELD TRIP SAFETY CHECK LIST

☐ Call ahead or visit the park or facility if you are unfamiliar with the area or the services available (water, bathrooms, food, fees, etc.).

☐ Establish a safe and direct route to and from your destination.

☐ Maintain adult to child ratios needed to insure the safety and well being of the children. Add extra staff if safety is a special concern (crowded area, limited visibility, etc.).

☐ Post trip information by the telephone in the office area or other pre-established location. Include route, destination, departure and return times, a list of the children and adults involved, field trip permission slips, and a cell phone number if available.

☐ Carry a first aid kit, health consent forms and emergency information for each child with you. Also include "as needed" medications for children with special health needs and directions for its use for that child. Use of sunscreen requires parental permission. At least one staff member must have a current first aid and CPR certificate.

☐ Plan to keep food/lunches cold and safe. Make arrangements for handwashing if running water is not available.

☐ Plan for frequent rest and water breaks between activities.

PERSONAL SAFETY CHECK LIST FOR CHILDREN

☐ Provide tags for each child with the name and phone number of your child care facility. If you do use individual names on the tag, use first name only.

☐ Make sure the adults are all familiar to each child.

☐ Establish a buddy system. Children with special needs may need to have an adult buddy.

☐ With parental permission, apply sunscreen (follow container directions) to each child as necessary.

☐ When you arrive at your destination, point out key landmarks and identify a "lost child" area.

☐ Teach children the steps to take if they get separated from the group:

1. Remain in the area where they last saw the group or go to the "lost child" area.

2. If possible, ask for help in an open visible place from someone in charge (ticket taker, clerk, etc,).

3. **NEVER** leave the area with an unidentified person.

4. Reassure the children that if they do become separated from the group, you will be looking for them. Count the group out loud so the children know you will know if someone is missing.

If you are using private cars, make sure there is a booster seat or seat belt available for each child and that the car is insured for transporting children.

If you are walking, review safety rules (safe street crossing, staying together, etc.).

If you are going by van or bus review those safety rules.

Healthy weight for healthy children with special health care needs

by Jean Trae, PhD, RD
Child Nutrition Coordinator, Nutrition Policy and Education Unit
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Weight, both underweight and overweight, is often an issue for children with special health care needs. Many conditions are characterized by poor growth and underweight. Children who have short stature and/or limited mobility are prone to excessive weight gain. Overweight in children with disabilities may impair their mobility, balance and ability to progress in gross motor skills. They are also at a higher risk for long-term health problems. Overweight may be a concern for children with cerebral palsy, congenital anomalies, develop-

please see page 5

continued from page 4

mental delay, Down syndrome, mental retardation, neuromuscular disorders, Prader-Willi syndrome, static encephalopathy, or spina bifida.

Although overweight in children with special health care needs is a cause for concern, weight loss should not be the central focus for addressing this problem. Maintaining a healthy weight should be the main goal for all children with special health care needs.

How do I know if my child is at a healthy weight?

Share results of the medical exam and the prescription with the school nurse or teachers so that the school becomes an important partner in your child's best interest.

Children go through several growth spurts. An accurate diagnosis of overweight or underweight requires measurements of height, weight, a visual assessment, and previous growth data to determine rates of weight gain over time. If it feels like your child is not growing into a healthy weight, talk with your child's health care provider. A medical examination may be helpful. If the doctor says your child is underweight or overweight, a referral to a registered dietitian and/or social worker may be the next step.

It is important to offer the child support and acceptance from the family. Don't focus only on the child's weight but make healthy eating and physical activity a fun goal for all family members.

Tips on helping children to maintain a healthy weight

- Give children the time and attention they need during meal or snack time. This impacts the amount they eat.
- Provide child-sized portions and amounts.
- Offer a variety of healthy foods in a child-friendly setting.
- Let children feel, mash, look, and smell the food to enjoy it.
- Satisfy your child's sweet tooth naturally with ripe bananas, sweet potatoes, winter squash, and dried fruits.
- Set a good example. If you eat the same food your child does, your example will be more influential than your pleading or reasoning.

Tips on managing the underweight child

A goal for an underweight child may be to increase calories without increasing the serving size. The child is more likely to eat most of the food if given a smaller portion.

Ideas for adding more calories to food are:

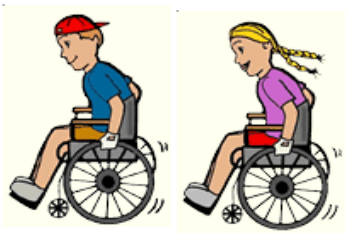
- Add powdered milk to fluid whole milk, milkshakes, juices, mashed potatoes, puddings, sauces, soups, and casseroles.
- Add eggs to baked goods, casseroles, ground meat dishes, pancakes and puddings **(uncooked egg or raw egg products should never be served).**
- Add pureed meats to casseroles, broth soups, cream soups and mashed potatoes.
- Add vegetable oils to casseroles, gravies, soups and vegetables.

Tips on managing the overweight child

The goal for overweight children is to maintain their weight until they catch up in height.

Ideas for reducing calories are:

- Change the family cooking methods. Instead of frying foods, try steaming, baking or broiling.
- Substitute low-calorie versions of high-calorie foods without reducing food items.
- Replace sugary or high-fat desserts with fresh fruits.
- Serve low-calorie, low-fat beverages like skim milk or water with meals and snacks for children over 2 years old.
- Participate in fun physical activities together with the child.



Playing it Safe with West Nile Virus

from Healthy Child Care, DHSS

With summer in full swing, so are the concerns about West Nile virus. It is important to remember that very few persons are actually at-risk for contracting West Nile virus in Missouri at this time. Transmission of the virus occurs when people become infected by the bite of a mosquito infected with West Nile virus. Even in areas where the virus is circulating, very few mosquitoes are infected with the virus; and the chances you will become severely ill from any one mosquito bite are extremely small. Less than 1% of

please see page 6

continued from page 5

persons infected with West Nile virus will develop severe illness. Among those with severe illness due to West Nile virus, case-fatality rates range from 3% to 15% and are highest among the elderly. People who are over age 50 have a higher risk for becoming seriously ill when they get infected with West Nile virus.

Mosquitoes become infected when they feed on infected birds, which may circulate the virus in their blood for a few days. Infected mosquitoes can then transmit West Nile virus to humans and animals while biting to take blood. The virus is located in the mosquito's salivary glands. During blood feeding, the virus may be injected into the animal or human where it can multiply, possibly causing illness.

Dead birds can help local health departments track West Nile virus. Check with your local health department about their policy on reporting dead birds. Persons should avoid bare-hand contact when handling any dead animals and use gloves and double plastic bags to place the carcass in a garbage can.

Mosquito Control

Reducing the mosquito population around your property is one of the most effective ways to reduce mosquito bites and can be accomplished by eliminating standing water:

- Dispose of tin cans, plastic containers, ceramic pots or similar water-holding containers.
- Remove all discarded tires on your property. Used tires are very significant mosquito breeding sites.
- Drill holes in the bottoms of recycling containers that are kept outdoors.
- Make sure roof gutters drain properly, and clean clogged gutters in the spring and fall.
- Turn over plastic wading pools and wheelbarrows when not in use. (If plastic wading pool is in approved childcare space, it must conform to all applicable licensing rules).
- Change the water in birdbaths and pet dishes at least weekly.
- Clean vegetation and debris from edges of ponds.
- Clean and chlorinate swimming pools, outdoor saunas, and hot tubs.
- Drain water from pool covers.
- Use landscaping to eliminate standing water that collects on your property.

Personal Protection During Outside Activity

It is not necessary to limit any outdoor activities. However, you can and should try to reduce your risk of being bitten by mosquitoes. Because mosquitoes are most active at dawn and dusk, you may decide to limit outdoor activities at these hours. You should also make sure all windows and doors have screens that are in good repair.

Insect repellents often contain very strong chemicals (e.g. DEET-look for its chemical name N,N-diethyl-m-toluamide) and should be handled and applied carefully, especially in the case of young children. Because young children's bodies are more sensitive to chemical exposures, and because some chemicals can affect fetuses, it is important to handle insect repellents carefully and avoid over-exposure by carefully following label instructions and the following guidelines:

- Keep repellents (and all chemicals) out of children's reach.
- Avoid using repellents on children less than two years old.
- Do not allow children to apply repellents themselves.
- Use only small amounts of repellent on children, and use repellents with 10% or less DEET by concentration.
- Do not apply repellents directly to children's skin; apply to your hands then on the child.
- Do not apply repellents near a child's eyes, nose, mouth, or hands to prevent accidental eye contact or ingestion.
- Avoid using DEET products on skin damaged by sunburn, cuts, rashes, or other skin conditions.
- Avoid breathing DEET products (especially sprays) by applying in well-ventilated rooms and not directly to the face. Apply to your hands and then rub carefully on the face.
- Avoid prolonged use of DEET products, and do not apply to skin that will be covered by clothing.
- Wash treated skin with soap and water upon returning indoors.

Because of concerns about children's reactions to insect repellent, parents should provide any insect repellent they wish to have applied to their child while in child care. In addition, childcare providers should have written parental permission on file before applying any insect repellent on children.

Please visit our SHCN website at *www.dhss.state.mo.us/SHCN/index.html* and the Family Partnership website at *www.dhss.state.mo.us/SHCN/FamilyPartnership/index.html*

DELIVERING ON THE PROMISE

MCHB funded F2F centers
***Last year's funding total (including Family Voices): $3,028,016**

Organization	Contact
Support for Families of Children with Disabilities; San Francisco, CA	Juno Duenas/ Linda Vossler-Swan (415) 282-7494 ext 15
Parent to Parent of VT; Williston, VT	Julie Arel, (802) 764-5920 ext. 28
Parent Advocacy Coalition for Educational Rights, (PACER), Inc.; Minneapolis, MN	Carolyn J. Allshouse, (952) 838-9000
Maine Parent Federation; Augusta, ME	Beverly J. Baker/ Janice LaChance (207) 623-2145
Family Voices of Tennessee at the Tennessee Disability Coalition; Nashville, TN	Dara Howe (615) 383-9442
Florida Institute for Family Involvement (FIFI); Crawfordville, FL	Conni Wells (850) 926-3514
Family Voices of Iowa at Access for Special Kids (ASK) Resource Center	Paula Connolly (515) 223-6714

continued from page 2

strengths and priorities of families are integrated into all aspects of the health care plan.

Family/professional partnerships

Active partnerships between families, youth, and professionals are the cornerstone of family-centered care. These partnerships support families in being integral partners with their children's medical home and in systems and policy development at the community, state, and federal level. This is critical if we are to improve services and supports to children and youth with special health care needs. For this reason, DSCSHN began funding activities that support "families as partners in decision-making at all levels and being satisfied with services they receive." The Integrated Services Branch of DSCSHN has had the program, "Family/ Professional Partnerships," for many years.

This program supports the development of partnerships between families and providers to better (1) organize mechanisms to educate, inform, and serve families with children with special health care needs; (2) assist family members with informed decision-making about the health and well-being of their own children and as partners in policy making for service systems; and (3) infuse cultural competence policies, practices, and values in health care.

The newest funded effort of this program is the Family-To-Family Health Information and Education (F2F) Centers. Instrumental in this effort has been Family Voices, which has been using family/professional partnerships to assist in developing F2F centers in every state.

Why F2F centers?

A national survey conducted by Brandeis University and Family Voices in 1999 showed that, although families want to be informed decision makers for their children, many times they can not consistently access accurate and quality information in a timely manner. Families also indicated that other families are often the most helpful in assisting them in obtaining and understanding information, particularly if it is a sustained state-level effort, formally organized and staffed with paid parents. Also, literature indicates that networks of informed families having similar issues and backgrounds (such as families with similar cultural, ethnic, and linguistic backgrounds) impact health behaviors of other families.

The F2F grants fund statewide, family-run centers that (1) develop and disseminate needed health care information to families and providers and respond to information gaps identified by both; (2) provide education and training opportunities for families; (3) integrate the philosophy and practices of family-centered care, family/professional partnerships, and cultural competence; and (4) collect and analyze data related to the core outcomes.

MCHB F2F center accomplishments

All of the F2F centers have devised ways to serve families statewide, from having statewide regional coordinators or liaisons with donated office space in community-based organizations, to coordinating networks of family-run organizations. Newsletters, information about trainings, and other materials are disseminated through these statewide structures. These centers provide individualized assistance to families and professionals by phone and visits, and conduct trainings and workshops for families and professionals on topics such as insurance changes, disabilities, and the medical home.

Most centers have trained and assisted families in becoming members of community and state advisory groups. Two centers use grant funding

please see page 8

continued from page 7

for a part-time social worker and a health care financial coordinator because of intense needs in these areas. Some of the centers have an additional focus of reaching out to families who might be under-served. These include families in rural and isolated areas or large urban areas, and families of diverse cultural and ethnic backgrounds, some with English as a second language. Two centers have materials in up to 10 languages, and one has a cultural competence advisory group.

Curricula have been developed to train parent staff and volunteers so that information provided to families and data collected are uniform. Data are collected on family needs, trends, and gaps in services and how families across the state are using the centers. All centers are attempting to collect the same data, particularly how changes in Medicaid and other health care financing services in states are impacting families.

The cooperative agreement with Family Voices provides technical assistance, particularly in developing a uniform database and a way of reporting data across centers so this information can be provided to state and federal partners for policy decisions. Family stories, putting a human face on statistics, are used with data to document needs for system changes and enhance state information obtained from the National Survey for Children with Special Health Care Needs.

For additional information . . .

- about this article, contact Diana Denboba, Maternal and Child Health Bureau, DDenboba@hrsa.gov, (301) 443-2370.
- about the President's Freedom Initiative, go to: http://ww.hhs.gov/newfreedom/final/hhsfull.html#intro.
- about Family Voices, contact Jennifer Cernoch, Executive Director, or Cindy White, Director of Fiscal Operations, (505) 872-4774 or kidshealth@familyvoices.org; website: www.familyvoices.org.
- about the National Survey for Children with Special Health Care Needs, see http://www.cdc.gov/nchs/slaits.htm or try the new MCHB funded Data Resource Center up in mid-March at http://www.schcndata.org.

The demand for center services has been tremendous. For example, in a three-month period:

- Seven centers received more than 11,000 requests for assistance from families (36%) and professionals (64%);
- Six Centers reported participating in over 400 meetings in which close to 5,600 people participated;
- Five F2F centers produced newsletters reaching more than 150,000 people and had over half a million website hits; and
- Four F2F centers reported distributing about 30,000 pieces of material to families and professionals (Draft 3rd Quarter 2003 Data Summary from Family Voices).

All of these activities are designed to enhance informed decision-making and partnerships at all levels and to increase family satisfaction with services.

Partner F2F centers

In 2003, our partner agency, The Centers for Medicare and Medicaid Services (CMS), in collaboration with MCHB also funded F2F Centers as a component of their Real Choice Systems Grants. These statewide centers will (1) provide education and training opportunities for families with children with special health care needs; (2) develop and disseminate needed health care and home and community-based services (HCBS) information to families and providers; (3) collaborate with the MCHB F2F centers to benefit children with special health care needs; and (4) promote the philosophy of individual and family-directed supports.

Although these are still in their first year, we expect to see benefits to families and providers in the grantee states of Alaska, Colorado, Indiana, Maryland, Montana, Nevada, New Jersey, South Dakota, and Wisconsin. For details, see www.cms.hhs.gov/newfreedom/rcc93003.pdf. O

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